

# NCRI Strategic Plan 2012–2017



NCRI

National  
Cancer  
Research  
Institute



# NCRI Partners





National Cancer  
Research Institute

Strategic Plan  
April 2012 – March 2017

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# Foreword

This third strategic plan for the National Cancer Research Institute builds on more than a decade of successful partnership. NCRI's ethos is one of communication, coordination and collaboration in order to add value to cancer research and avoid unnecessary duplication. Now that government and charity funders spend over £500m per year on cancer research, it is more important than ever to be working together to ensure that maximum value is achieved from this huge investment. Most of this funding comes from the public in the form of taxation or through voluntary donation and we therefore have an obligation to see that it is spent widely and wisely for the benefit of the public, and especially for cancer patients.

NCRI's role is to make connections. We look at the strategies of our Partners and identify areas of common interest. We aim to avoid or overcome fragmentation, which means that we do not have a separate research strategy of our own but operate in a way that is responsive to the Partners and their needs.

In our early years we have successfully stimulated new research on a diverse range of topics including prostate cancer, prevention through lifestyle changes, and supportive and palliative care. The current agenda includes radiotherapy, early diagnosis and inequalities in cancer outcome linked to factors such as older age, social deprivation, gender and ethnicity.

In our new strategic plan we will continue to develop our current programme as well as set ourselves new objectives that relate to our core business and these are summarised in the plan. To give a flavour of the rich variety of research topics that we address we have included in the text a selection of vignettes relating to our work. Of course these do not represent a comprehensive list and there are many more projects that we are working on currently or have aspirations to address in the future. These will be reviewed and published separately during the course of the coming period.

In summary our new strategic plan is wide ranging, flexible and ambitious but by working together in partnership we are confident that we can meet the many challenges which lie ahead and reach NCRI's major goal of adding real value to cancer research.

Professor Dame Janet Husband DBE  
Chair

# Summary

## Mission

Our mission is to ensure best value from Partners' investment in cancer research by working together in areas of common interest, especially those which are considered to be priorities by, and for, patients and the public.

## Objectives

The following relate to core business and to the overarching management of strategy and priorities. Objectives relating to the operation of individual initiatives and projects will be published and reviewed separately, as appropriate.

NCRI will continue to pursue a portfolio of topic-specific initiatives and other activities, some managed through the NCRI Secretariat and some by individual Partners.

Specifically we will:

- Introduce new processes to regularly review and give direction to the full portfolio of NCRI actions; these will be piloted in 2012 and fully in place by 2013
- Continue to collect Partners' portfolio data on an annual basis until at least 2015; longer terms plans will be subject to a review
- Undertake a detailed analysis of the first 10 years of NCRI portfolio data by 2013
- Further develop the NCRI Cancer Conference:
  - Delegate numbers to top 2000 on a regular basis by 2016
  - Increase bilateral relationships with Royal Colleges and professional bodies (at least one per year)
  - Improve financial performance (subject to environmental factors)
- Continue to play a leading role in the expansion of the International Cancer Research Partnership with a view to compiling representative international portfolio data by 2015
- Review all international links in 2013
- Collect and disseminate information on the impact of NCRI initiatives, starting in 2012
- Re-focus NCRI Board business on high level strategy and decision-making whilst creating more opportunities for Partners to debate topics



The NCRI Secretariat also will continue to recognise and promote the intangible benefits of partnership which are less easy to measure. These include:

- Maintaining an environment in which the involvement of patients and carers in research is considered to be the norm
- Fostering effective communication among Partners and with the wider community of researchers and other funders, especially smaller charities
- Providing neutral ground on which Partners and others can come together to discuss any topic relevant to cancer research
- Challenging organisations and individuals to break down artificial barriers and embrace the benefits of working together
- Maintain its role in research intelligence

# 1. Introduction: Building on more than

In 2011 NCRI celebrated 10 years of partnership. During this time the amount of money spent by NCRI Partners on cancer research in the UK doubled to around £500m per annum, and the number of patients enrolled in clinical studies in the UK increased fourfold. We have also established a national database of cancer research funding, inaugurated a major annual conference, and successfully promoted the involvement of patients and carers in cancer research. During the next period, we will build on these achievements, whilst continuing to adapt the way we work to respond to a changing environment.

NCRI comprises 7 government partners, 14 charities and the Association of the British Pharmaceutical Industry (ABPI) working together and with patients and carers. NCRI is open to new members who fulfil the following criteria:

- Expenditure of at least £1m per annum on cancer research in the UK, which is expected to be sustained at that level
- Funding decisions made on the basis of peer review of proposals invited through open competition (for charities, membership of the Association of Medical Research Charities will be taken as evidence of this)
- Willingness to submit portfolio data to the NCRI Cancer Research Database annually
- Willingness to share portfolio data, including financial information, with national and international partners

Amongst Partners, our ethos is one of mutual respect and individual autonomy, recognising that the diversity of our organisations enriches our efforts. Most of the approx £500m spent by government and charity partners each year is public money, either raised through taxation or donated voluntarily, so we have a duty to the public to spend that money wisely.

The keys to our working relationships are communication, coordination and collaboration. In the first instance we need to understand each other as organisations – each Partner has a different mission, stakeholder community and accountability structure. Each Partner develops its own research strategy and scientific priorities, and it is not the role of NCRI to do this on their behalf. NCRI monitors Partners' strategies and plans, and through the NCRI Cancer Research Database acquires detailed knowledge about what research each Partner is supporting. This sharing of information enables us to look for common ground where Partners can work together, either through coordination to ensure that individual activities complement each other, or through collaboration on joint projects to address gaps in the portfolio. Analysis of the portfolio helps to avoid unnecessary duplication.

# a decade of partnership

The need for coordination and the ethos of partnership have not changed significantly since 2001. At the same time, relationships among Partners, and with external stakeholders, have developed to a point where there is confidence in our ability to make greater progress by working together in certain areas of research, ie those

which have either not received necessary attention, or that have proven challenging in the past. As the partnership has matured, we have become more outward-looking and devote more attention to facilitating interactions between the scientific community and research funders, so that each has greater clarity on what the other has to offer. Our experience with a variety of models for collaboration has taught us to tailor actions to circumstances, and the vignettes in this document illustrate the success of this approach. While circumstances will change, this principle of tailoring actions will not, and our work will continue to develop through evolution and adaptation rather than any radical change. We remain committed to the principle of added value, only getting involved when we can help to achieve something that the Partners cannot do alone.



This Plan addresses NCRI's approach to partnership and core business and some examples of successful actions are illustrated in vignettes. More detailed information on ongoing actions will continue to be available via the NCRI website ([www.ncri.org.uk](http://www.ncri.org.uk)).

## 2. Research environment: Opportunities

### Resilience

The period of this Plan will be a challenging time for medical research, financially and organisationally. Innovation is nevertheless an essential investment for the future and it is important to maintain a level of ambition, whilst also being realistic about what is achievable, and how. Although governments in the UK are needing to reduce expenditure, commitment to medical research through Health Departments and the Medical Research Council is buoyant, and the general public continue to make generous voluntary donations to charities, especially those concerned with cancer. The scientific opportunities, building on advances in genomics, molecular biology and computational science are manifold and make this an exciting time to be involved in cancer research. As an illustration of confidence in the sector, construction has begun in London of The Francis Crick Institute, which will be a major new centre for innovation across a range of medical research areas; this will open its doors in 2015.

### The NHS as an environment for research

The NHS continues to provide important opportunities for research throughout the UK – much of this is taken forward in the clinical research networks, and in collaboration with industry. More specifically for NCRI, there are opportunities to facilitate the development of a research culture within health service environments, and to encourage the development of research capacity in groups of health professionals for whom this has not in the past been a well-defined career path.

#### Growth in accrual to clinical trials since 2001

Across the UK as a whole, the National Cancer Research Network has raised the number of patients entering clinical trials from less than 4% in 2001/02 to 18.3% in 2010/11. In England one in every five newly diagnosed patients is now participating in a trial. Also in England,

the last 10 years have seen the delivery of more than 1,100 clinical research studies, including 180 commercial trials. A workforce of over 700 individuals work on over 500 open studies. More than 250,000 people have taken part in these studies.

Restructuring of the NHS in England will also provide challenges for clinical research. Whilst the commitment to research in the NHS is strong at leadership level, there could be unforeseen consequences due to the extent of structural change at local level. The

National Cancer Intelligence Network in England is also due to move from the NHS to become part of Public Health England, and the implications for research based on cancer intelligence data will need to be assessed. These changes come at the same time as we prepare for a more stratified approach to cancer medicine, enhancing the complexity of the challenge. It will help that the cancer research networks within the NHS in England, Wales, Scotland and Northern Ireland, which together form the UK's National Cancer Research Network (NCRN) are now well established and are expected to continue to flourish.

## Cancer and other diseases and conditions

Just as patients may experience more than one disease or condition, so cancer research does not operate in isolation, and many of our Partners support the full spectrum of research across all areas of health and disease. We have found that initiatives which start in cancer (such as the clinical research networks) may be transferrable to other diseases once their value is proven. In other cases we tackle research areas which are more broadly applicable than cancer from the outset. Examples include research in prevention and end of life care. Increasingly we are likely to consider interactions between cancer and other diseases and conditions, especially in older patients. We aim to break down silos and avoid putting up new barriers between cancer and other fields, so that knowledge and experience are widely shared. In part we do this by being inclusive in our working relationships: we work with many organisations which are either too small to be NCRI Partners or whose focus is not primarily cancer.

### The NPRI consortium

In 2002 only 2.4% of the NCRI portfolio (£6.3m) addressed prevention research. Through NCRI, it was decided to create a dedicated funding stream, to be operated by Medical Research Council and known as the National Prevention Research Initiative (NPRI) to support research on risk factors including poor diet, physical inactivity, obesity, smoking and alcohol consumption. As these factors

also increase risk for other diseases, it was possible to bring in support from other funders such as the British Heart Foundation and Diabetes UK. Grants totaling £23m had been awarded by 2011 with a further £10m pledged by 16 partners for phase 4. The share of the portfolio has gone up to 3.4% in 2010 (£17.1m) showing growth in excess of the doubling in the portfolio overall.

## **Financial environment**

There have already been subtle changes to the way we work, recognising that less money is available for new initiatives than in the past. We now channel more effort into activities that help or enable the research community to tap into existing funding streams for priority research topics, and expect this to continue. This includes helping cancer researchers hone their grantsmanship skills and explore the full range of funding schemes, especially to ensure that cancer competes for the available funds effectively against other research needs within disease-generic funding schemes.

Another trend is the increasing opportunity for research provided by existing datasets, which enables new research to be undertaken without the cost of collecting new data. This is illustrated by the work of the National Cancer Intelligence Network (NCIN) to develop the National Cancer Data Repository (NCDR) linking data from cancer registries and other NHS sources such as Hospital Episode Statistics (HES) and radiotherapy statistics. Further linkages will be developed through the Clinical Practice Research Datalink (CPRD) launched by the government in December 2011. There is also considerable scope for linking and/or re-using data collected for research rather than healthcare; these resources may arise from clinical trials or cohort studies and may include biosamples as well as data. During the first decade of the twenty-first century much work has been done on the regulation and governance of access to personal data for research, and the research community is now poised to generate a substantial amount of new knowledge and understanding by this cost-effective means.

## **Involving patients and carers in research**

Patients and carers are now established as a stakeholder group whose involvement in the planning and delivery of studies is essential to successful research, especially in clinical studies which enrol patients or other volunteers as direct participants. In 2008 we stated 'Our vision for 2013 is that there will have been a culture shift towards acceptance of consumer involvement as the norm in all aspects of research'. This vision is well on the way to being achieved, both within cancer and beyond, and we are proud that NCRI has set examples in this area, and that we have been able to share that experience with colleagues working in other disease areas within the NIHR Patient and Public Involvement programme.

## The ProtecT trial

Patient involvement can make the difference between success and failure in a clinical trial. ProtecT is evaluating the effectiveness, cost-effectiveness and acceptability of treatments for localised prostate cancer. A group of patients were interviewed to explore how they would react to information about the study. Changes were made as a result. 'Study' was seen as something more systematic than 'trial' which was associated with 'try

and see'. The non-radical intervention arm was presented first, then the treatment arms, to help emphasise equivalence. The non-radical intervention arm was renamed 'active monitoring'; having previously been termed 'watchful waiting' or 'conservative monitoring'. These latter terms were taken to indicate inaction: 'watch while I die'. After these changes, participation rose from 40% to 70% of patients invited.

## Smaller charities

NCRI works with a variety of other organisations with an interest in research and who do not meet the criteria for membership. For example, there are many small charities which specialise in a particular tumour type, providing valuable information, support and services to patients and families. Some also support research and although they cannot foresee being able to spend as much as £1m per annum, they nevertheless wish to have a relationship with NCRI and where possible participate in our actions. Other organisations may share an interest in a topic such as prevention, or end of life care, without being a cancer funder at all. NCRI aims to be inclusive in its relationships and permissive in respect of joint activities, whilst maintaining consistency in how we define the membership that is at the core of what we do.

## Working with industry

The commercial sector plays an essential role too in bringing innovation into practice whether it be through drugs, diagnostics or equipment. The Association of the British Pharmaceutical Industry (ABPI) was a founding partner in NCRI and continues to provide a conduit to productive working relationships with individual companies. Welcome impetus will come from the Westminster Government's "Plan for Growth" which will run for the whole of the Parliament due to run till 2015, and which highlights



'healthcare and life sciences' as one of the sectors it particularly wishes to grow in the UK.

In December 2011, the Prime Minister went further in announcing a life science strategy with new money for a catalyst fund to help commercialise new medical treatments, and also a commitment to make more NHS health data available for research.

There is a commitment to overcome unnecessary barriers and speed up regulatory processes through the establishment of a Health Research

Authority which also came into being in December 2011. The aim of this is to streamline regulation, create a unified approval process, and promote proportionate standards for compliance and inspection within a consistent national system of research governance in England.

NCRI will continue to seek, and to value, support from the commercial sector for the NCRI Cancer Conference. To complement the collaborative work with pharma being taken forward throughout the UK by the National Cancer Research Network and Experimental Cancer Medicine Centres (ECMCs), NCRI has wider opportunities to explore in relation to the biotech industry, diagnostics and medical equipment manufacturers. Links have developed piecemeal in different initiatives and as a result have not all had high visibility. In the coming years NCRI will seek a greater level of engagement from companies at a more strategic level. One of the keys to success will be to build on established personal and organisational relationships.

## AstraZeneca working with NCRN across the UK

The Alliance Programme between AstraZeneca (AZ) and the UK-wide National Cancer Research Network, started in 2008 when AZ saw that a collaboration with the NCRN and the NCR Clinical Studies Groups would provide seamless expertise in clinical academic science, trial design and delivery, enabling faster development of their pipeline of novel compounds. The UK clinical academic community and cancer research networks welcomed the opportunity to

design and deliver innovative phase II trials, often in patient populations that would not normally have access to novel compounds. The full pipeline of post-phase I, pre-licensed compounds is made available for studies in patient populations outwith the industry-sponsored phase II/III licensing programme. At 2012 there are 25 phase II studies running, and similar alliances are being developed with other companies.

## International links

NCRI must also consider its international environment, and where value can be added through international collaboration. The most important and fruitful activity on which the NCRI Secretariat leads is the coordination of portfolio data through the International Cancer Research Partnership (ICRP – see page 18). However, there are also important activities led by the National Cancer Research Network and individual Partners involving, for example, collaboration on behalf of the whole of the UK with the US National Cancer Institute (NCI) and the European Organisation for Research and Treatment of Cancer (EORTC) on trials in rarer cancers through the International Rare Cancers Initiative (IRCI). A fresh overview of international links will be compiled so that Partners can see their efforts in this broader context.

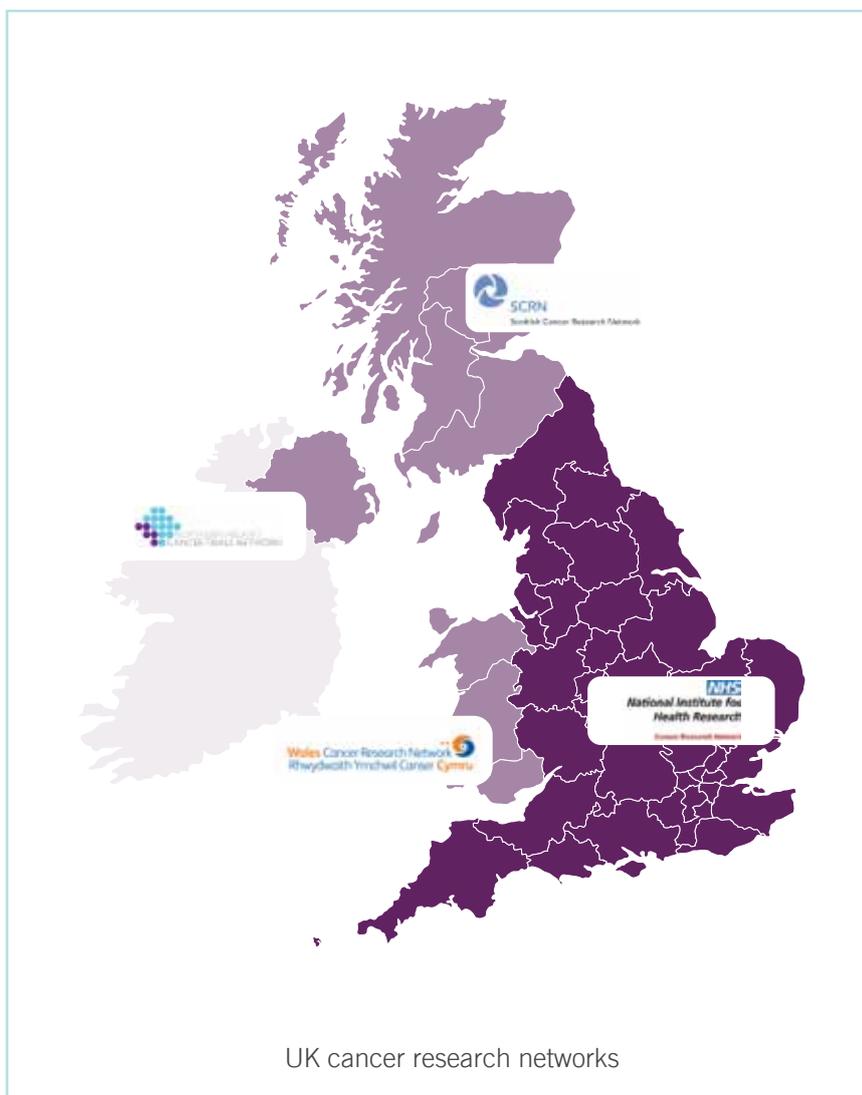
# 3. Research environment: National network

## The interconnectedness of cancer research

Complementary to the work of NCRI has been the development of three nationwide networks which provide an infrastructure for cancer research which is the envy of other countries. These are managed independently of NCRI and provide essential underpinning resources for much of the work of NCRI Partners both individually and collectively.

## National Cancer Research Network

The National Cancer Research Network (NCRN) provides researchers with the practical support they need to make cancer clinical studies happen in the NHS, so that more patients can take part. It comprises the National Institute for Health Research (NIHR) Cancer Research Network in England, the Scottish Cancer Research Network, the Wales Cancer Research Network and the Northern Ireland Cancer Trials Network, each funded by the relevant government health department. The NCRN has a proven track record and world class reputation for increasing participation in clinical research, raising the number of patients entering clinical studies from 4% of newly-diagnosed patients to 18% in its first 10 years. In parallel with this the number of industry trials adopted into the NIHR portfolio in England topped 200 in 2011.



These networks will continue working at national and local levels developing and implementing the portfolio of studies, engaging with stakeholders including industry, patients and public, and ensuring that their research is translated into benefits for patients. Much of the study development work is undertaken through the Clinical Studies Groups who are supported by NCRI.

NCRI is particularly involved in a workstream focusing on 'portfolio balance and delivery' which aims to promote uptake of trials in the networks in areas such as surgical research, radiotherapy and palliative care research, as well as seeking to fill gaps in the portfolio of trials itself. As already mentioned, NCRN also has strong international collaborations with the USA and Europe, especially in relation to the International Rare Cancers Initiative.

## Experimental Cancer Medicine Centres



The Experimental Cancer Medicine Centres (ECMCs) undertake early phase and biomarker studies. They are jointly funded by Cancer Research UK and the government health departments. The ECMCs' vision is that they will bring together laboratory and clinical patient-based research to speed up the development of new therapies and individualise patient treatment. Most of their studies involve no more than a few centres unlike the larger studies run through the National Cancer Research Network. National networking remains important and will be a particular focus in the next quinquennium, for example as a focus for working with industry, standardising quality assurance (QA), and developing a common understanding of regulatory requirements. Selected ECMCs are also participating in Phase I of the Cancer Research UK Stratified Medicine Programme. ECMCs are currently funded up to 2017.

## National Cancer Intelligence Network



The National Cancer Intelligence Network (NCIN) was established in June 2008 to bring together a wide range of organisations with an interest in cancer intelligence. The Network's core objectives are:

- Promoting efficient and effective data collection throughout the cancer journey
- Providing a common national repository for cancer datasets
- Producing expert analyses to monitor patterns of cancer care
- Exploiting information to drive improvements in cancer care and clinical outcomes
- Enabling use of cancer information to support audit and research programmes

Early work supported mainly by the NHS in England has concentrated on the merging of a variety of English NHS datasets and publication of analyses which, where possible, have been UK-wide in scope. NCRI Partners are involved (i) to encourage the use of NCIN data for investigator-led research which would be funded through existing peer review funding schemes, and (ii) to promote UK-wide harmonisation and linkage of

data. Achievements so far include the preparation of a generic access policy for data and biomaterials, linkage of cancer data to the General Practice Research Database (GPRD), and the generation of over 40 research projects using NCIN data. NCIN is also working with Macmillan Cancer Support to understand the pattern of service use by patients who have been diagnosed with different cancers, to inform service planning and more directly help cancer survivors of the future.

During the next period, the NCIN dataset will be further enriched. The NCIN is managing a major programme of modernisation across all eight English cancer registries, which will see the creation of a unified national cancer registration service by the end of 2012. This will provide more timely and comprehensive data, creating ever more new opportunities for research, and for linking in to the work of other initiatives and partners' strategies.

## Radiotherapy

Following a review in 2008, NCRI provided funding for a Clinical Lead (one day a week) and full-time coordinator to support the Clinical and Translational Radiotherapy Research Working Group (CTRad). At that time Britain was lagging behind in the evaluation and introduction of new technologies. With around 80 members from several disciplines, CTRad has generated the enthusiasm and critical mass for effective collaborations on

technology development and across all phases of trial. Projects include industry-targeted publications, educational workshops, and think tank meetings to help departments build their local capacity. Triallists now benefit from a central fund secured by CTRad for quality assurance, and twice-yearly proposal guidance meetings. More trials and programme grants are now being funded.

## Positron Emission Tomography (PET)

The NCRI PET Research Initiative provided support to coordinate three strands of activity – facilitating late phase trials, overcoming the barriers to early phase research, and establishing a Core Lab that sets QA standards and a network of NCRI-accredited PET sites. The first two workstreams have transitioned their work back into the research community

in 2011 having successfully resolved a number of issues. The trials network will be maintained as will the Core Lab, which is the envy of other countries, and will continue to provide QA support for future trials, develop scanning standards for new tracers and participate in international standardisation work.

## The infrastructural role of NCRI

In addition to the nationwide networks, NCRI contributes to the provision of research infrastructure in areas that need a collective approach by research funders.

The most important of these areas are:

- Support for the secretariat for the Clinical Studies Groups which generate new clinical trials. This work is expected to continue throughout the period of this plan
- Support for the 4 workstreams of the Clinical and Translational Radiotherapy Research Working Group (CTRad), currently funded to 2015
- Interim support for a PET core lab providing QA for research scans, to become fully self-supporting within the next 3 years
- Coordination of cancer biobanking, which is separately funded until 2013 after which it will be subject to review



## 4. Research themes

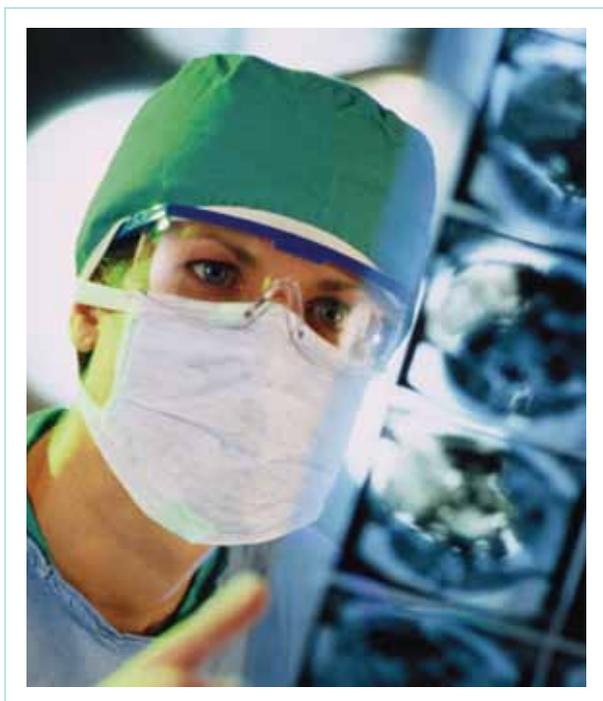
When we look for common interests among funders, we find them most often in research of direct relevance to patients, and also to members of the public for whom risk, prevention and early presentation of symptoms are equally important issues. This is not to deny the great strength of basic science funded by individual Partners, and the importance of translating discovery into patient benefit. Since NCRI started to collect data on the cancer research supported in the UK in 2002, 40% of the Partners' combined portfolio has consistently comprised cancer biology, and this is

likely to continue. Most of this research is response-mode rather than strategic funding, ie it is the best ideas that get funded, recognising that long-term applicability cannot be fully predicted. For this type of work, openly competitive peer review is an effective tool for maintaining a high quality portfolio. In the areas of research which are closer to patients' needs and nearer to application, variables are not so easily controlled and a mixture of scientific disciplines and research methods may be needed. This in turn requires different approaches to the support of research, such as dedicated funding, greater facilitation, or provision of special infrastructures. These are the approaches that NCRI promotes.

In 2008 we highlighted five high-level aspirations for cancer research which we placed at the heart of NCRI's work. These are a synthesis of areas of common interest among Partners and the Partners wish these to remain the NCRI's overarching

framework. They also align with government health strategies for England, Wales, Scotland and Northern Ireland in which there is a particular emphasis on improving outcomes for cancer patients. NCRI will continue to foster research aimed at:

- Better prevention leading to a lower cancer risk for each individual;
  - It has been estimated that as many as half of all cancers are preventable by changing lifestyle and/or avoiding environmental exposures
- Earlier diagnosis so that cancer is more often identified at a stage when it can be treated effectively;
  - Where cancer does occur, earlier diagnosis will enable better outcomes with less severe treatments for patients in terms of survival and quality of life. It has been estimated that 5–10,000 deaths could be avoided in England each year through earlier diagnosis



- Better, cost-effective treatments for patients, and more people cured of their cancers;
  - New targeted therapies will be more effective and only used in patients known to be capable of benefitting, thus improving outcomes and reducing wastage
- Less inequality in outcomes for patients;
  - The National Cancer Intelligence Network has highlighted that older people and those experiencing social deprivation have poorer outcomes for cancer. For some cancer types there are also discrepancies linked to gender or ethnic group
- Improvements to the health and quality of life for people who survive cancer;
  - There is still much to be learned about the medical, psychological and social needs of patients once they have completed front-line treatment and for those who experience recurrence of cancer and who later move into end of life care

Each of these aspirations potentially covers a very wide range of research and many challenges. They are not mutually exclusive, and as such are not used to categorise initiatives. Rather they act as a series of themes which pervade all of NCRI's work.

### National Awareness and Early Diagnosis Initiative (NAEDI)

NAEDI aims to improve cancer outcomes through earlier diagnosis. It comprises a variety of local, national and international projects. NCRI Partners (Cancer Research UK, Health Departments and the Economic & Social Research Council) have provided two rounds of grant funding for research in areas such as promoting

public awareness of symptoms, improving the uptake of screening, and addressing delays in both primary and secondary care. A NAEDI research conference was held in 2011 and further events will be held to help develop an interactive research community in this area.

In addition to themes and topics, NCRI also addresses common cross-cutting needs such as access to human tissue, and seeks to encourage professional groups who do not yet have a strong research culture, to develop one. These are areas where a partnership approach can be more effective than individual funders working alone. Another important theme is the translation of new discoveries into benefits for patients and public, which can often be a lengthy process of development and evaluation. A balance needs to be struck between the rigour of evaluation and the time taken to complete it and then to introduce improvements once they have been confirmed as such. This continues to be a source of tension and while NCRI is not in a position to get directly involved in the translation process, we help to promote discussion and debate around the choice of appropriate study methods or the need for new methods.

# 5. Core activities

## Cancer Research Database (CaRD)

Up to early 2012, the NCRI Secretariat has collected and analysed 10 years of research funding data from Partners. Data is captured at the level of individual projects and programmes and includes an abstract of research, names and affiliations of principal investigators, duration of support and financial value. Each project is classified according to the Common Scientific Outline (CSO) (<https://www.icrpartnership.org/CSO.cfm>) which codes both the area of research and tumour type, where relevant. While there are caveats as to the interpretation of the data, particularly when looking at narrow topics which receive a small proportion of funds, it has been used to:

- Track the doubling of the portfolio as a whole between 2002 and 2010
- Illustrate strengths in basic science and therapeutic research
- Highlight less well-funded areas such as prevention, supportive and palliative care and lung cancer research – this has led directly to joint funding initiatives
- Look for long term trends
- Enable individual Partners to analyse their own portfolios and compare them with the national picture
- Inform other NCRI projects or respond to external requests
- Provide a basis for information sharing with research funders in other countries – the UK is seen as one of the leaders in the International Cancer Research Partnership (ICRP) in which portfolio data is pooled and analysed at international level
- Make aggregate financial information openly available on the web for those interested to undertake further analysis



### Trends in tumour-specific research

About 40% of the cancer research portfolio consists of research targeted at one or more particular types of cancer. While the portfolio as a whole has doubled between 2002 and 2010, research on some tumour types has grown at an even faster rate. Annual spend on lung cancer has grown from 3.4% of site-specific research (£3.5m) in 2002 to 5.5%

(£11.8m) in 2010. Similarly research on oesophageal cancer has grown from 1.2% (£1.2m) to 2.5% (£5.4m) and pancreatic cancer from 1.2% (£1.2m) to 2.0% (£4.4m). Although the sums are still relatively small, this is good news because these are among the most fatal and difficult to treat cancers.



Analysis of this portfolio data was the trigger for much of NCRI's early work and whilst it no longer drives the agenda in the same way, many other uses in the list opposite remain valuable to Partners.

Opportunities for the next stage of development of portfolio analysis include:

- Recruiting more cancer research funders from continental Europe, and beyond, into the international partnership which is currently dominated by USA, UK and Canada. This is being supported by EU grant funds and is not expected to incur a cost to NCRI Partners beyond the current investment in collecting UK data
- Publication of international analyses which will show the UK position in an international context
- More sophisticated analytical tools. These are being developed by the US National Cancer Institute (NCI) at their cost and will be made available through the international partnership
- Following the signing of data sharing agreements by over 50 organisations in 2010, NCRI Partners now have on-line access to project level data, including financial information, for all those organisations and can perform their own analyses on topics of interest, for example for internal strategy discussions (publication is subject to appropriate permissions)
- Development of a read-across between the Common Scientific Outline and the Health Research Classification System (HRCS) developed by the UK Clinical Research Collaboration
- Exploration by some individual Partners of text-mining software which may in due course replace manual coding. Pilot work is currently under way

In order to capitalise on these opportunities, Partners have agreed to continue to collect data annually, in the current form, for the foreseeable future. However, there may come a time when fewer new insights are being gained, and it may be appropriate to consider less frequent data collection; or automated technologies may have developed to a stage where they meet the need cost-effectively. A review along these lines should be considered before the time of the next strategic plan. This could also usefully consider whether data on outputs and impacts could be linked in.

The ICRP is not a vehicle for joint research funding, neither would NCRI or ICRP wish it to be so. It does have the potential for greater sharing of information, experience and strategic thinking than just portfolio information. For example, there is an established evaluation sub-group and library of evaluation reports available online.

## NCRI Cancer Conference



The NCRI Cancer Conference has been an annual event since the autumn of 2005. It provides a venue for dissemination of research across the full range of relevant disciplines including basic, translational, clinical, psychological and social research. The NCRI aims for top quality in all aspects of the conference programme and its delivery, bringing in speakers of the highest calibre from around the world to present to an audience which itself is increasingly international. Importantly the NCRI Cancer Conference has also become known as a networking event for professionals at all levels, resulting in new connections and collaborations. No other cancer conference

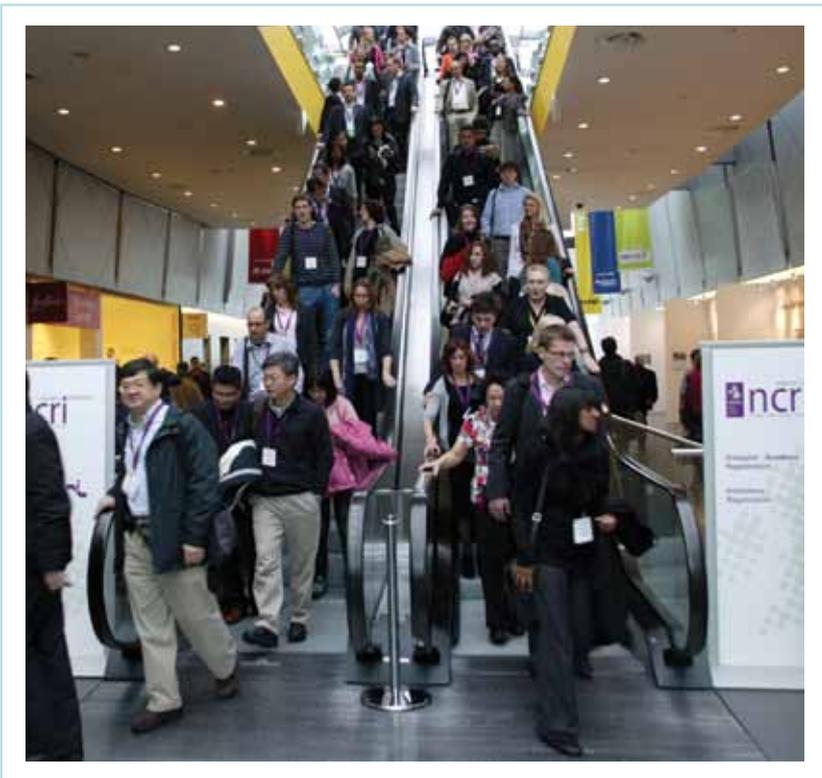
in the UK is able to achieve this effectively across such a range of disciplines – these intangible benefits are hard to measure but undoubtedly enrich the research effort. The NCRI Cancer Conference has also pioneered the involvement of patients and carers in the planning of, and attendance at, a big national conference. We also attract commercial organisations from a variety of sectors, as delegates, sponsors and exhibitors.

Following a successful transfer from Birmingham to Liverpool in 2010, NCRI Partners have renewed their commitment to the conference as an annual event until at least 2014. After only 7 years, it still has much potential for development. Whilst

pleasing such a wide range of delegates can

be a challenge, feedback suggests that a good balance is achieved between laboratory and clinical sciences; clinical attendance is rising and we aim to continue this trend.

The structure of the core programme for the conference is now tried and tested, and development work focuses on additional components that can be grafted on. To date this has included a schools' visit, prize award ceremonies, arts events and satellite scientific meetings. During the next period, we will continue to enrich the programme,



and aim to achieve growth in delegate numbers to 2,000, as well as continuing to move towards financial self-sustainability. A new relationship with the Royal College of Radiologists has been agreed for 2012 and plans are being made to work with other Colleges and professional bodies.

### International portfolio analysis

The EU is funding the development of cancer portfolio analysis across Europe, providing NCRI with an opportunity to pass on its expertise in use of the Common Scientific Outline through training workshops. Initially 14 organisations are participating from countries including Germany, France, Netherlands, Austria, Spain and Italy. This work is part of a broader programme known as

TRANSCAN which promotes coordination and collaboration in translational cancer research. The full network (in which Cancer Research UK is the formal UK representative) extends to 25 partners in 19 countries in the European Research Area (which also includes, for example, Israel and Turkey), providing scope to achieve a fairly full coverage of European cancer research funding eventually.

# 6. Communication and engagement

The stakeholders in cancer research are many and diverse: in addition to our own Partners and other research funders, the Secretariat, on behalf of the Partners, needs to listen to the voices of researchers, patients, clinicians, other health professionals, NHS managers, government policy-makers, regulators, collaborators in industry, research funders in other countries, and others. The role of the NCRI Secretariat in maintaining awareness of activities and making connections has led to the development of a very large web of contacts for a relatively small organisation. This, plus the increased sophistication of electronic media, means that effective communication has become increasingly important to NCRI and requires more resource than in the past. The mainstays of our communication strategy are, and will continue to be, web pages, newsletters and the annual NCRI Cancer Conference. We will renew efforts to use the NCRI Cancer Conference more effectively as a vehicle for communication about NCRI activities and also aim to keep pace with modern technology, for example use of digital tools such as RSS feeds, and a Twitter account (sparingly used).



Involvement with patients and carers (sometimes referred to collectively as consumers) is entering a new phase as NCRI establishes a consumer networking group comprised of lay members appointed to sit on the NCRI Board and other initiatives led by the Secretariat. There will continue to be close working with the NCRI Consumer Liaison Group (CLG) managed through the NIHR Cancer Research Network Coordinating Centre in Leeds. The new group (Hub), established at the request of the consumers, will discuss broad issues of interest across the partnership and provide strategic context to the work they do on the Board or other committees. This networking will supplement the more specific briefings for meetings already provided by the Secretariat. The agenda will thus be distinct from, and add value to, the activities within the NIHR Patient and Public Involvement programme.

## 7. Impact of NCRI

The impact of NCRI's work is open to evaluation at a number of levels. Some of the most important benefits are the intangible ones – these include bringing people together in new groupings, whether it be at the NCRI Cancer Conference, or through initiatives, or the Secretariat's intelligence function. Portfolio analysis or collective opinion on a given topic, which is compiled and reflected back to the research community can also influence a range of individuals and organisations. Harder outputs include a variety of reports and jointly funded research or infrastructure initiatives, and these are captured in annual operating reports which are published on the NCRI website.

Real impact comes from the outcomes of research and these may be in a variety of forms including basic understanding of biological mechanisms, new therapeutic discoveries, clinical trials which lead to changes in practice and direct benefit to patients or development of research capacity. Many NCRI Partners have their own evaluation tools for assessing the productivity of their own research and some Partners work collaboratively in this area outside of NCRI. The NIHR Cancer Research Network also has its own workstream looking at impact.

During the period of this plan, NCRI will become more proactive in evaluating the impact of partnership initiatives. Individual Partners have existing evaluation tools which it may be appropriate to adopt in some cases, for example the MRC's e-Val system, the NIHR's Awards Assessment Tool and the evidence briefings prepared by ESRC. With clearer definition of objectives and success factors at the start of new work in future, it should be possible to embed evaluation in the management of the project from the outset. Issues to be addressed will include which audiences might need to learn of the impacts: for example, government policy makers, service commissioners, service providers or members of the public. Other considerations will include the tools to be used, who should be primarily responsible for the evaluation and how it will be resourced. Timing should also be considered as some projects will take longer to have an impact than others. The amount of effort should always be proportionate to the scope of the initiative and likely benefits. Where possible a similar approach to evaluation will be taken with initiatives already running.

In some circumstances, it may be difficult to disentangle the impact of NCRI's contribution from those of individual Partners, or from the wider international community of researchers. In such cases it may be more informative to examine progress through collective effort in a given field using methods such as bibliometrics or research investment, and indicators such as changes in clinical practice.

# 8. Governance and implementation: N

NCRI will continue to operate as a partnership organisation, with Partners agreeing strategies and actions through the NCRI Board, and with the NCRI Secretariat putting them into action, working with individual Partners and others, as required. All Partners are committed to the ethos of the partnership and to the core activities described in this plan. While decisions on specific initiatives are also made collectively, Partners each retain the freedom to participate or not, so differing sub-groups of Partners will form consortia for different purposes. NCRI has no legal status and can only operate on the basis of consensus and persuasion. It is especially important that the Secretariat seeks the common ground among stakeholders, without generating a separate agenda of its own. Partners rely on the NCRI Secretariat to act as the physical embodiment of NCRI and as a focus for communicating NCRI actions.

NCRI aims to be both flexible in how it approaches each topic for action, and responsive to changes in priority, for whatever reason. Flexibility also includes the ability to tackle short or long-term projects. NCRI must retain the capacity to tackle long-standing issues that are too large, expensive or complex for a single organisation, and that clearly need a national approach and/or require multi-stakeholder involvement.

## Mesothelioma

In 2010, the Department of Health asked NCRI to undertake a review of research in mesothelioma and other asbestos-related diseases. To avoid delays to other work, the project was outsourced with close supervision by the NCRI Secretariat and expert advisors. With support from the British Lung Foundation (BLF) a literature search and survey of the research

community were performed, leading to a report summarising current knowledge and areas of research need. This fed into a workshop and call for research proposals by the BLF with funding from the insurance industry. New research in mesothelioma is being supported as a result.

At other times there is a need for a re-ordering of priorities to accommodate a newly identified need or to make space in the work programme for a short additional piece of work. These factors mean that a fixed workplan for a number of years is no longer realistic. Instead, the NCRI Board will regularly review and give direction to the full portfolio of NCRI actions being taken forward by the Secretariat and by individual Partners. In doing this, the Board will also determine when current initiatives should come to a timely end, and what new topics may need to be addressed.

# CRI Board and Secretariat

## Survivorship and End of Life Care

In 2009 a number of NCRI Partners became aware that they had introduced new research strategies without being fully aware that others had been doing the same. There was a lack of understanding as to how well these new strategies might align and what messages to give the research community. The NCRI Board asked the Secretariat to delay other priorities and to undertake a rapid review

of survivorship and end of life care which pulled the new strategies together in a single framework as well as repositioning the priorities for partnership working. This was published in 2010 and was followed by a number of actions including the provision of grantsmanship resources, setting up of an end of life care research interest group, and a survivorship research planning workshop.

As NCRI is not a legal entity, it is necessary for the NCRI Secretariat to be hosted by an organisation which can employ staff, provide office accommodation and services, and act as banker and contractor for services. Cancer Research UK fulfils this role with appropriate costs reimbursed from the Secretariat budget. This arrangement is expected to continue for the foreseeable future.

In addition to running a multiplicity of projects and workstreams, the NCRI Secretariat has developed an important role in research intelligence – keeping a finger on the pulse of what is going on in all but the most basic aspects of cancer research. The Secretariat is well placed to scan the horizon for new developments coming down the track which may merit NCRI's attention. Closely allied to this is the ability to make connections between activities run by other organisations (which may include NCRI-badged initiatives) which may not otherwise be in communication with each other. One example is that issues relating to the management of biosample resources overlap with those relating to managing health data in the NCIN; another is that the equalities agenda overlaps with those of both the NPRI and NAEDI. Issues of research capacity, specialist training or health economics crop up in many contexts. The Secretariat also maintains awareness of Partners' evolving strategies and looks for commonality there. Many more examples could be cited and it is a distinctive part of the NCRI Secretariat's role to be on the lookout for new connections at all times.

# Appendix. Glossary of terms

ABPI	Association of the British Pharmaceutical Industry
BLF	British Lung Foundation
CaRD	Cancer Research Database
CPRD	Clinical Practice Research Datalink
CLG	Consumer Liaison Group
CSGs	Clinical Studies Groups
CSO	Common Scientific Outline
CTRad	Clinical and Translational Radiotherapy Research Working Group
ECMCs	Experimental Cancer Medicine Centres
EORTC	European Organisation for Research and Treatment of Cancer
GPRD	General Practice Research Database
HRCS	Health Research Classification System
ICRP	International Cancer Research Partnership
IRCI	International Rare Cancers Initiative
NAEDI	National Awareness and Early Diagnosis Initiative
NCDR	National Cancer Data Repository
NCI	National Cancer Institute (US)
NCIN	National Cancer Intelligence Network
NCRI	National Cancer Research Institute
NCRN	National Cancer Research Network (UK-wide)
NHS	National Health Service
NIHR	National Institute for Health Research
NPRI	National Prevention Research Initiative
PET	Positron Emission Tomography
UKCRC	UK Clinical Research Collaboration

# Notes



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